



Burden and Coping Strategies Adopted by the Caregivers of Mentally Ill Client

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Abstract

Illness is an abnormal condition which affects human being and cause burden for the family members who care for them, present study focused on the physical, psychological, social, financial burden and coping strategies among caregivers with

Objective: i) to assess the burden and coping strategies, ii) to compare the burden and coping strategies, iii) to find association between burden and coping strategies iv) identify the relationship between the burden and coping strategies

Material and Method: Descriptive survey approach to assess the burden and coping strategies among the caregivers of mentally ill clients, Shrirampur, Data were collected from 100 caregivers of mentally ill clients; the modified semi structured tested interview schedule was used to collect data from 06/01/2014 to 08/02/2014.

Results: Descriptive and inferential statistics were used for analysis, findings in relation to demographic data of caregivers revealed that (26%) were in the age group of 29 to 38 years, (60%) were male, (26%) had secondary education, (48%) had agriculture as a occupation, (76%) had less than Rs 5,000 monthly income, (33%) were parents, (67%) living with relative, (22%) had health problems whereas demographic data of mentally ill clients revealed that (49%) were in the age group of 21 to 30 years, (36%) had affected with schizophrenia, (85%) had average burden.

Overall burden mean score (31.85+7.96) which is (32%), higher mean score was obtained in financial aspect (9.05+2.10) which has (45%) indicates that caregiver had mild burden, overall coping strategies (78.58+8.89) which has (46%), higher mean score was obtained in the psychological/ emotional aspect (20.43+2.34) which has (46%) indicate that caregiver followed partially adaptive coping strategies.

There is a significant association between burden and age (4.55), living with patient (4.33), duration of caregiving (4.71), category of mental illness (6.00) and duration of mental illness (5.93) and between coping strategies and previous experience regarding caregiving (4.80) and duration of mental illness (4.91) and there is no association found with other socio demographic data. Relationship between burden and coping strategies shows r value for no burden: (-0.49), mild: (-0.06), moderate: (-1). These values interpret that there is negative relation among burden and coping strategies.

Conclusion: Findings of the study reveals that caregivers had a mild burden and partially adoptive coping strategies in all aspects, there is an association between burden and coping strategies of caregiver with their selected socio demographic data and negative relation between burden and coping strategies, which may be by experience caregivers adopt various coping strategies as burden occurs.

Keywords Coping Strategies, Burden, Caregiver, Mental Disorder Client

Introduction

Being a care giver is the most thankless role in the world.

Marcia Wallance

Individual is a single human considered a part from a society or community. As we live in the world every individual faces different situations and responds them in a unique way. Many factors such as cultural background, past experience, emotional attitude, a circumstance varies from person to person.

World Health Organization (WHO) has defined health as, a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Health is an important fundamental human need.

Health problems are explained as a state in which you are unable to function normally and without pain, while, mental illness is a medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions that often result in a diminished capacity for coping with the ordinary demands of life. Mental illness refers to a wide range of mental health conditions disorders that affect your mood, thinking and behaviour. Serious mental illnesses include major depression, schizophrenia, bipolar disorder,

obsessive compulsive disorder (OCD), panic disorder, posttraumatic stress disorder (PTSD).

In Indian culture now also most of the population lives in joint family by the emotional bonding, caregivers is a person from the family or a nearest person from the family who know the patient needs. Caregivers have a major role to play in re-socialization, vocational and social skills training of a relative with mental illness as guide, teacher, counselor, coach and administrator. Caregivers of persons with chronic mental illness are usually family members they are the individuals whose own happiness is entwined with the well-being of people who are dear to them. The burden of care is associated with significant stress.

Mental illness

Effects on the Patient like quality of life, poverty, social problems, vulnerability to abuse and additional health problems.

Effects on Families or Caregiver like psychological disorders are often unable to work at full capacity due to the demands of caring for a mentally ill individual, leading to decreased economic output and a reduction in household income. Loss of



income and the financial costs of caring for a mentally ill person put these households at an increased risk of poverty. Family members may also experience significant and chronic stress due to the emotional and physical challenges of caring for a mentally ill family member.

Need of the study

WHO (2012) estimated that More than 450 million across the globe suffer from mental illnesses. Schizophrenia, depression, epilepsy, dementia, alcohol dependence and other mental, neurological and substance-use disorders make up 13% of the global disease burden, surpassing both cardiovascular disease and cancer. WHO states that by 2030, depression will be the second highest cause of disease burden in developing countries and the third highest in under developing countries?

In the last 45 years, suicide rates have increased by 60% worldwide. More than 90% of people who kill themselves have a diagnosable mental disorder. Suicide is among the three leading causes of death among those ages 15-44 years in some countries, and the second leading cause of death in the 10-24 years age group. In the UK, 70% of people affected by mental illness experience discrimination, and discrimination believed to be worse in developing countries. Mental and psychosocial disabilities are associated

with rates of unemployment as high as 90%. Meanwhile, those with severe mental illnesses are more likely to have other health risk factors.

Botswana (2006) investigated the experiences of families caring for a mentally ill family member for distribution of caregiver responsibilities, most families reported that lack of financial and medical resources at the family and community levels made it difficult and stressful to provide adequate care.

Statement of Problem

“A Study to assess the Burden and Coping strategies adopted by caregivers of mentally ill clients in UNDE hospital, shrirampur”

Objectives

- To assess the burden and coping strategies adopted by caregiver of mentally ill persons
- To compare the burden and coping strategies of caregiver with their selected socio demographic variables.
- To find association between burden and coping strategies of caregiver with their selected socio demographic variables.
- To identify the relationship between the burden and coping strategies in caregiver of mentally ill persons.

Operational Definitions

Burden:



➤ According to Teber's dictionary (2010) it is the perception of stress and fatigue caused by the sustained effort required in caring for condition with special need for care.

➤ In the context of present study, it is the subjective perception of distress experienced by the caregivers of mentally ill person as assessed with help of modified burden scale.

Coping Strategies:

➤ According to Collins dictionary (2008) Coping strategies refer to the specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events.

➤ In the context of present study, it is the subjective expression of action/ measures taken by the caregivers to overcome the burden and its severity, which assessed by modified coping strategies tool.

Caregiver:

➤ According to medical dictionary (2002) "one who provides care to a dependant or partially dependant patient in an acute care setting, the caregiver is most often a professional, however in the home care situation, person is a family member".

➤ In the context of the present study, caregiver is a individual and present during tje data collection period between 18 to 58

years of age who is taking care the mentally ill person.

Mental Disorder Client:

➤ According to medical dictionary (2007) "any of various psychiatric conditions, usually characterized by impairment of an individual's normal cognitive, emotional or behavioral functioning and caused by physiological or psychosocial factors.

➤ In the context of the present study, individual who are suffering with any kind of mental disorder and from the UNDE hospital for treatment.

Assumptions:

The assumption for the present study is

- Caregivers have some burden
- Caregivers use some coping strategies
- Socio demographic variables influence the burden and the coping strategies
- The Burden have impact on psychosocial activities

Delimitation

The study was limited to the caregiver of mentally ill client who were,

- Healthy to perform care activities
- Willing to participate in the study
- Living with the mentally ill person
- Present during the period of data collection

Review of literature



Aggarwal M, Avasthi A, Kumar S, Grover S (2011) stated that concept that takes into consideration both negative and positive consequences of the disorder and coping of caregivers, were assessed by Experience of Caregiving Inventory (ECI), Coping Checklist (CCL) result show that maximum ECI score was seen in negative domains of handling the difficult behavior followed by negative symptoms, loss and dependency and significant positive correlation was seen between total positive ECI score and the level of education of caregivers and study conclude with education of caregivers, coping strategies used by the caregivers and available social support influence the final appraisal of caregiving.

Kumar R, (2012) mentioned that chronic illness of a family member is an objective stressor that results in strain for the caregiver or relative because of the difficult tasks of caring for that person and is likely to affect both the physical and mental health of caregiver, 32 relatives/caregivers were interviewed using semi-structured “Family Burden Interview Schedule (FBIS)” and “Coping Checklist (CCL)”. Findings of the study revealed more often, caregivers adopt positive cognitive coping strategies followed by distraction and problem-solving to overcome burden due to patient’s illness.

Research methodology

Research approach- Non experimental

Research design- descriptive study design with exploratory survey approach

Setting of study- UNDE hospital shrirampur, Ahmednagar

Population- All caregivers of the mentally ill client

Sample - caregiver of mentally ill client who were present in the UNDE hospital, shrirampur during the data collection period

Sample size - 100

Sampling technique- Purposive sampling method

Inclusion criteria

This study include person

- Healthy to perform care activities
- Willing to participate in the study
- Living with the mentally ill person
- Present during the period of data collection

Tool

The semi structured interview schedule was prepared in three sections

Section I It consists of two parts, **Part A:** Socio-demographic data of caregiver of mentally ill clients **Part B:** Socio-demographic data of mentally ill clients

Section II: Modified burden scale, to assess the burden of caregiver of mentally ill clients **Section III:** Modified coping



strategies, to assess coping strategies of caregiver of mentally ill clients

Ethical clearance

Ethical clearance was obtained

Reliability

The reliability of the tool was tested by implementing the semi structured interview schedule on 10 caregivers of mentally ill clients attending the psychiatric OPD; the split half reliability method was used to test the reliability of modified burden and

modified coping strategies tool and the r value was 0.93 and 0.85 respectively

Validity

Content validity of the semi structured interview schedule was established by consulting with the experts the validity was established by consulting the expert dept of department of psychiatry, department of psychology, department of mental health nursing, statistics and language. The tool was modified according to the suggestion and recommendation of experts in consultation with guide.

Major Findings

Table 4.1 Description of Frequency and percentagewise Socio demographic data of Caregivers mentally ill client

SN	Variables	Frequency	Percentage
1	AGE		
	18 – 28	20	20 %
	29 – 38	26	26 %
	39 – 48	21	21 %
	49 – 58	21	21 %
	59 and above	12	12 %
2	GENDER		
	Male	60	60 %
	Female	40	40 %
3	OCCUPATION		
	Daily Wages	25	25 %
	Agriculture	48	48 %
	Private	6	06 %
	Government	2	02 %
	Business	4	04 %
	Housewife	11	11 %
	Any other	4	04 %
4	MONTHLY INCOME (RS)		
	BELOW 5,000	76	76 %
	5,001 – 10,000	14	14 %
	10,001 – 15,000	6	06 %
	ABOVE 15,000	4	04 %
5	MARITAL STATUS		
	Married	80	80 %
	Unmarried	10	10 %
	Divorced	1	01 %
	Widow/ Widower	9	09 %
6	LIVING WITH PATIENT		



	Yes	67	67 %
	No	33	33 %
7	DURATION OF CAREGIVING (YRS)		
	Below 1	66	66 %
	1 – 5	28	28 %
	6 – 10	2	02 %
	Above 10	4	04 %
8	AVERAGE TIME SPENT FOR GIVING CARE (HOURS/DAY)		
	Below 5	23	23 %
	6 – 10	29	29 %
	11 – 15	29	29 %
	16 – 20	02	02 %
	Above 20	17	17 %
9	PREVIOUS EXPERINCE		
	Yes	6	06 %
	No	94	94 %
10	HEALTH PROBLEMS		
	Yes	22	22 %
	No	78	78 %

Table 4.2 Description of Frequency and percentagewise Socio demographic data mentally ill client

SN	Variables	Frequency	Percentage
1	AGE OF MENTALLY ILL CLIENTS IN YEARS		
	Below 10	03	03 %
	10 – 20	09	09 %
	21 – 30	49	49 %
	31 – 40	17	17 %
	41 – 50	09	09 %
	Above 50	13	13 %
2	GENDER		
	Male	55	55 %
	Female	45	45 %
3	DURATION OF MENTAL ILLNESS (YEARS)		
	Below 1	62	62 %
	1 – 5	31	31 %
	6 – 10	03	03 %
	Above 10	04	04 %
4	MONTHLY EXPENDITURE ON MEDICINE (IN RUPEES)		
	Below 1000	89	89%
	1001 – 1500	11	11%
5	NUMBER OF EPISODES		
	1 ST	56	56 %
	2 ND	30	30 %
	3 RD	08	08 %
	4 TH	04	04 %

5TH

02

02 %

Section III

a) Assessment of mean, SD and mean percentage of aspects of caregiver's burden scores of mentally ill clients

SN	AREA	Maximum score	MEAN	SD	MEAN %
1	PHYSICAL ASPECTS	32	7.16	03.74	22.37
2	PSYCOLOGICAL/ EMOTIONAL ASPECTS	32	8.75	03.36	27.34
3	SOCIAL ASPECT	16	6.89	01.16	43.06
4	FINANCIAL ASPECT	20	9.05	02.10	45.25
5	OVERALL	100	31.85	07.96	31.85

b) Assessment of mean, SD and mean percentage of aspects of caregiver's coping scores of mentally ill client

SN	AREA	Maximum score	MEAN	SD	MEAN %
1	PHYSICAL ASPECTS	40	15.11	03.55	37.77
2	PSYCOLOGICAL/ EMOTIONAL ASPECTS	44	20.43	02.34	46.43
3	SOCIAL ASPECT	28	14.16	02.02	50.57
4	FINANCIAL ASPECT	20	9.28	02.65	46.40
5	OTHERS	40	19.6	02.00	49.00
6	OVERALL	172	78.58	08.89	45.68

Section V: find the association between Burden and Coping Strategies among Caregivers of mentally ill client

df = 1

Table value = 3.84

(P > 0.05 not significant)

Chi square Finding reveals that there is a significant association between Burden of caregivers who live with patient, duration of care giving, category of mental illness and duration of mental illness in mentally ill client.

Chi square Finding reveals that there is a significant association between coping Strategies of caregivers who had previous experience and duration of mental illness.

Section V: Relationship between the burden and coping strategies in caregiver of mentally ill client

The calculated co- efficient of co-relation test value revealed that among the selected study variables like burden and coping strategies of caregivers of mentally ill client indicate negative co- relation between them with the r value for no burden: (-0.49), mild: (-0.06), moderate: (-1). These values interpret that there is negative relation among burden and coping strategies.

Implications:

Implication of the study can be discussed in 4 broad areas namely; nursing practice, nursing education, nursing administration and nursing research.

Nursing practice:

❖ This study findings providing information on burden and coping strategies among the caregivers of mentally ill clients

❖ Nurse plays an important role in prevention, promotion, curative care of mental illness.

❖ Findings of this study will help the nursing personnel to working in mental health services, hospitals, community areas and rehabilitation centre to improve their knowledge.

❖ Findings also help the nursing personnel to plan for the nursing care.

❖ Findings of the study provide the knowledge on counseling services, minimizing the burden and improving coping strategies for caregivers of mentally ill clients



❖ Findings would help the nurse practitioner to assess and manage the burden

Nursing education:

❖ The study findings explain the importance of burden and coping strategies more theoretical and practical aspects of stress management can be included in the curriculum

❖ Nurse educator should educate the student nurses and other health care workers to improve the knowledge and create awareness regarding caring mentally ill client

❖ Community psychiatric nurse should do survey to find out cases of mental illness, burden of caregivers, coping strategies adopted by caregivers.

Nursing research:

❖ Study focus on to the burden and coping strategies among the caregivers of mentally ill client

❖ These findings helps nurse researcher to develop conceptual framework, carry out research activity on various aspect of burden and coping strategies among caregivers of mentally ill clients

❖ Long term research with interventional study can also be done on burden and coping strategies among caregiver of mentally ill client.

Recommendations:

On the basis of findings of the present study following recommendations were made.

❖ This study can be conducted on larger samples

❖ This study can be conducted in different settings which will help in comparison

❖ Study can be conducted specific of various aspect of burden and coping strategies

❖ An experimental study can be conducted by using psycho education

❖ Study can be conducted to explore the family caregiving experiences of persons with serious mental health problems

❖ Study can be done to evaluate the burden and QOL of caregivers with mentally ill client

❖ Study can be conducted to explore risk factors that may aggravate care burden and impact on caregivers

❖ Exploratory study can be conducted to identify positive and negative coping strategies adopted by family members of mentally ill client

❖ Comparative study can be done to evaluate the QOL between specific disease conditions.



Bibliography

1. Sr. Nancy. Principles and practice of nursing. 6th edition. Indore: NR publication; 2006.
2. Park K. Preventive and social medicine. 22nd edition. Jabalpur; banarasidas bhanot publication; 2013.
3. WHO Mental Health GAP Action Program
4. Kate Torgovnick May September 11, 2012 at 3:15 pm EST TED Blog Global Issues TEDTalks Some stats on the devastating impact of mental illness worldwide, followed by some reasons for hope)
5. Van den Bergh, B.J., Gatherer, A., Fraser, A., Moller, L. (2011). Imprisonment and women's health: concerns about gender sensitivity, human rights, and public health. *Bull World Health Organ*, 89: 689-694.
6. Greenberg, G.A., Rosenheck, R.A. (2008). Jail incarceration, homelessness, and mental health: a national study. *Psychiatric Services*, 59(2): 170-177.
7. Seloilwe, E.S. (2006). Experiences and demands of families with mentally people at home in Botswana. *Journal of Nursing Scholarship*, 38(3): 262-268.
8. Mavundla, T.R., Toth, F., Mphelane, M.L. (2009). Caregiver experience in mental illness: a perspective from a rural community in South Africa. *International Journal of Mental Health Nursing*, 18: 357-367.
9. Deswal BS, Pawar A. An epidemiological study of mental disorders at Pune, Maharashtra. *Indian J Community Med*. 2012 Apr;37(2):116-21. doi:10.4103/0970-0218.96097. PubMed PMID: 22654285; PubMed Central PMCID: PMC3361794
10. Henry Brodaty, Marika Donkin, *Dialogues Clin Neurosci*. 2009 June; 11(2): 217–228.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/>
11. Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: roles of caregiver characteristics, caregiving burdens, and satisfaction with psychiatric services Daniel Fu Keung Wong^{1*}, Angus Yuk Kit Lam¹, Sau Kam Chan² and Shuk Fan Chan² *health and Quality of Life Outcomes* 2012, **10**:15 doi:10.1186/1477-7525-10-15 <http://www.hqlo.com/content/10/1/15>
12. Coping By Owen Kelly, Ph.D. Updated August 24, 2010 http://ocd.about.com/od/glossary/g/Coping_Glossary.htm
13. Chapter 14. Supporting Family Caregivers in Providing Care Susan C. Reinhard, Barbara Given, Nirvana Huhtala Petlick, Ann Bemis <http://www.ahrq.gov/professionals/clinicia>



- ns
14. Oxford dictionary (assumption)
 15. Teber's dictionary 2010, (burden)
 16. Collins dictionary 2008, (coping strategies)
 17. Medical dictionary 2002, (caregiver)
 18. Medical dictionary 2007, (mentaly ill client)
 19. Pautasso M. ten simple rules for writing a literature review [cited on: 13/3/2014] available from URL: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3715443>
 20. WHO. World Mental Health Survey Consortium; Prevalence, Severity, and Unmet Need for Treatment of Mental Disorders in the World Health Organization World Mental Health Surveys. *JAMA*. 2004. 2581-2590. Doi:10.1001/jama.291.21.2581.
 21. J. Alonso, Angermeyer M, S. Bernert. Prevalence of mental disorders in Europe. Results from the European Study of the Epidemiology of Mental Disorders project; 14/6/2004 - [DOI: 10.1111/j.1600-0047.2004.00327]; 109 (s420). Pages 21–27.
 22. Kessler RC, Berglund P, Demler O, Jin R, Kathleen R, Walters EE. Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Co morbidity Survey Replication. *Archives Psychiatric Nursing*. 2005; 62(6):593-602. [Doi:10.1001/archpsyc.62.6.593].
 23. Jane Costello E, Mustillo S, Erkanli A, Keeler G, Angold A. Prevalence and Development of Psychiatric Disorders in Childhood and Adolescence. *Archives Psychiatric Nursing*. 2003; 60(8):837-844. [Doi:10.1001/archpsyc.60.8.837].
 24. Alonso J, Chatterji S, Lee S, Ormel J, Ustün TB, Wang PS. The global burden of mental disorders. *Epidemiological psychiatric society – 2009, Jan-Mar*; 18(1):23-33.
 25. Koujalgi SR, Patil SR. Family burden in patient with schizophrenia and depressive disorder: *Indian journal of psychological medicine* [doi: 10.4103/0253-7176.119475]; 2013 Jul; 35(3):251-5.